Research Paper

Patients’ perceptions of the usability, utility and impact of a same-day self-administered routine electronic patient-reported outcomes (PRO) assessment in HIV care in two North American clinics

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We assessed patients’ perceptions of the utility and impact of a same-day self-administered tablet-based patient-reported outcomes (PRO) assessment integrated into routine HIV care in two North American clinics. People with HIV (PWH) self-administered a PRO assessment inclusive of psychosocial and behavioral topics prior to their routine care visit. Providers were given succinct summary results before seeing the patient. We conducted semi-structured 1:1 interviews after appointments assessing utility and perceived impact of PROs. We coded themes using qualitative software. PWH (n=30; mean age 48) reported PROs facilitated honest responses, improved recall, enriched communication, expanded comprehensiveness of care, and promoted self-evaluation. Several PWH reported feeling more ‘cared about’ when asked about mental health and quality of life-related needs. PWH found PROs administered before the routine care appointments were useful for prioritizing discussion topics with their providers, initiating discussion of sensitive issues, and improving comprehensiveness of/satisfaction with care.

Key words: Patient-reported outcomes, HIV care.

INTRODUCTION

HIV, in its emergence as a manageable chronic condition (Hogg et al., 1998; Palella et al., 1998; Murphy et al., 2001) has ushered in an era in HIV care of emphasizing the management of comorbidities over the life course and
an opportunity to focus on improving quality of life. As such, modern HIV care requires a multidimensional assessment of patient health that queries and helps contextualize mental health, symptoms, and health behaviors. These areas are often most easily and accurately elicited by patient report. Both people with HIV (PWH) and their HIV care providers have prioritized the importance of assessing domains such as depression, medication adherence, substance use, sexual risk behavior, HIV-related stigma, intimate partner violence, and social support as part of routine care (Fredericksen et al., 2015, 2019). However, in HIV care many of these domains are commonly under-addressed and inadequately or not assessed (Messiah et al., 2001; Gross et al., 2002; Conigliaro et al., 2003; Morin et al., 2004; Crane et al., 2017). Time constraints, social desirability bias, and language/culture barriers are common reasons (Kissinger et al., 1999; Williams et al., 2002; Narayan, 2010).

Routine, systematic elicitation of patient report, through the use of patient reported measures, also known as “patient reported outcomes” (PROs) (U.S. Department of Health and Human Services and Federal Drug Administration 2006), improves provider detection and ability to address multiple difficult-to-measure domains of care "Crane et al 2017". PROs have been useful to providers in HIV and other care settings (Wolfe et al., 2003; Irwin et al., 2015; Fredericksen et al., 2016), improving patient outcomes (Ruland et al., 2010; Cleeland et al., 2011; Basch et al., 2016, 2017), detection of symptoms (Velikova et al., 2004; Mark et al., 2008a; Sharma et al., 2016), adverse health behaviors (Berry et al., 2011; Crane et al., 2017), and mental health issues (Espallargues et al., 2000; Crane et al., 2017), and by helping providers to prioritize the most relevant concerns (Mark et al., 2008a; Fredericksen et al., 2016). PROs improve patient-provider communication, by helping patients take inventory of their needs, empowering them to raise concerns, and facilitating discussion of sensitive topics (Wagner et al., 1997; Taenzer et al., 2000; Brown et al., 2001; Detmar et al., 2002; Velikova et al., 2004).

From the patient perspective, studies have shown that PROs increase satisfaction with care (Wasson et al., 1999; Taenzer et al., 2000; Chen et al., 2013; Nelson et al., 2015). However, to ensure sustained success of use of PROs in clinical care, patients must find PROs acceptable to use, easy to self-administer, and useful to their goals. A multisite quantitative study among PWH assessing patients’ perceived ease and acceptability of using PROs in their care found that a 10-12 minute assessment of health domains including antiretroviral (ART) adherence, sexual risk behavior, intimate partner violence, depression, substance use, and others, self-administered via touch screen computer tablets on-site prior to the appointment with results delivered to the provider prior to meeting, to be highly acceptable (Fredericksen et al., 2020). However, few studies have interviewed patients at length about the acceptability of PROs. While a few qualitative studies with patients in other types of care settings have found such assessments acceptable and usable (Wasson et al., 1999; Wolpin et al., 2008; Wu et al. 2011, Jones et al., 2014; Sarabia et al., 2015, Stover et al., 2015; Sharma et al., 2016), to date, there has not been a published qualitative assessment asking PWH themselves how they perceive the value and impact of PRO assessments in their care.

To address this, we assessed patient perceptions of the utility and impact of a same-day, self-administered, tablet-based patient-reported outcomes (PRO) assessment that had been integrated into their routine HIV care in two North American clinics.

METHODS

Background

These interviews were part of a larger evaluation project, the PROgress study, which sought to understand the effectiveness and impact of implementing a self-administered touch screen electronic PRO into clinical HIV care in two North American HIV care outpatient clinics: the Midway Specialty Care Center (MSCC) in Ft. Pierce, FL, USA, and St. Michael’s Hospital (SMH), Toronto, Canada, between August 2018 and July 2020. A full description of the PROgress study is available at https://progresshivcare.org/.

Sites

We selected the study sites based on interest in exploring PRO implementation in their practice, the number of providers to experience the intervention, caseload, and patient demographic clinical, and geographic diversity. MSCC in rural Ft. Pierce, FL, serves ~1500 patients, with a high rate of uninsured and impoverished patients, 60% of whom are women and over half of patients are ethnic minorities. SMH in Toronto, Ontario, is an urban outpatient hospital-based clinic serving ~1800-2000 PWH; 70% are men, with a high proportion of men who have sex with men (MSM).

Participating PWH

The study included English-speaking adults (aged ≥ 18 years at

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study entry) with a diagnosis of HIV infection who were attending one of the participating clinics for a routine visit during the study period and had completed the PRO on that day. Those with known acute or significant prohibitive psychiatric, cognitive, or motor impairment, or those who appeared acutely intoxicated, were excluded.

Recruitment

The local research coordinator invited a convenience sample of patients at each site to participate in an individual qualitative interview occurring immediately after their routine clinic visits (same day) during which they had been administered the PRO. Patients were either telephoned in advance of their appointment to invite them to stay later for the interview, or offered the interview immediately after the appointment. Patients were assured that choosing to participate or not would not impact their care and that all information would be kept confidential prior to de-identification. We intentionally oversampled members of ethnic minority groups and women. All project activity was approved by respective Human Subjects Review entities (SMH through its institution-based Research Ethics Board, and MSCC through the University of Washington’s Institutional Review Board).

PRO assessment

We selected instruments for the PRO assessment based on their brevity, validity, and potential to inform decision-making during the visit. We built on the lessons learned from PRO integration into the Centers for AIDS Research Network of Integrated Clinical Systems cohort (Kitahata et al., 2008). Input from clinical site team facilitated further tailoring for site-specific needs. The PRO assessment at both sites included: mental health (depression/suicidal ideation [PHQ-9] (Spitzer et al., 1999, Kroenke et al. 2001), anxiety [single item from HIV symptom index] (Justice et al., 2001), health behaviors (antiretroviral adherence (Simoni et al., 2006; Lu et al., 2008), substance use [ASSIST, AUDIT-C] (Bush et al., 1998; Bradley et al., 2003, Newcombe et al., 2005), nicotine use (Kiechl et al., 2002; Nance et al., 2017), sexual risk behavior (Frederiksen et al., 2018); contextual factors (housing status (Whitney et al., 2020), intimate partner violence [IPV] (Fitzsimmons et al., 2019), and other forms of screening (nutrition [Canadian Nutrition Screening Tool] (Laporte et al., 2015), attitudes toward medications [2 items from HATQOL] (Holmes and Shea, 1998), sexual orientation, gender identity). Measures unique to individual sites included a review of symptoms measure at MSCC; SMH used a measure querying Canadian citizenship status, as well as a measure querying sex practices under the influence of illicit drugs. We applied skip logic wherever possible to minimize patient response burden. The number of questions included in the assessments ranged from 65 to 101 at MSCC and from 51 to 1 at MH. Patients self-administered the PRO assessment in electronic format on a touch-screen iPad tablet. A small number of questions appear to the patient on the screen at a time with large radio-buttons next to each response option. Once the patient has made their selection on the final question on the page, a new screen with subsequent questions automatically appears. Patients have the ability to move forward and backward through the PRO using navigational arrow icons at the base of the screen, and may skip a section without answering by using the forward button. They may also change their response from an earlier screen by navigating there using the “back” button. A progress bar at the bottom of the screen indicates the proportion of the PRO assessment that has been completed and how much content is left. A “help” button is visible throughout the assessment, in case patients have questions about or difficulty with the assessment; use of this button prompts real-time response from staff to check in.

Automated algorithms generated PRO scores and results. Patient completion of the PRO automatically prompted the printing and/or electronic transmission of a 1-page summary of results which was shared with the provider immediately prior to seeing the patient.

Interview guide development

Two seasoned qualitative researchers with expertise in evaluating patient perceptions of PRO data collection in HIV care developed the interview guide in conjunction with team members with expertise in health evaluation research and clinical HIV care. Areas of inquiry were informed by previous study findings with PWH on this topic (Frederiksen et al., 2019), as well as content from a validated scale of acceptability adapted for evaluating PROs (Tariman et al., 2011), and included ease of use, perceived impact on patient-provider communication, and perceived impact on quality of care. Sample questions included: “Do you think having your provider see your answers to these questions affected their ability to take care of you/give you good quality care? Why or why not?”, “How do you imagine that it would be different, if at all, if your provider were instead verbally asking you these questions?”, and “In your opinion, do you think taking the PROs affected how the appointment went? If so, how?"

Interviews

We conducted semi-structured individual interviews lasting up to 60 minutes, querying ease of completing the PROs, interest in responding to the questions, any perceived changes in the patient-provider communication due to the provider receiving a summary of the PROs, perceived impact on their care, and interest in having the clinic implement PROs as part of their standard practice during routine office visits. Patients were remunerated at the equivalent of $50 USD. Qualitative data were collected by digital recorder and transcribed.

Analysis

Qualitative data were coded using Dedoose qualitative software (v. 8.3.41) by two trained, seasoned qualitative researchers (RF, EF). We initially coded within general pre-established thematic areas based on the interview questions: usability of PRO platform, perception of general value of the PROs to their care, perceived impact on communication with their provider, and criticisms/recommendations for improving its use in care. Two coders independently identified key concepts within each category using an open-coding method, and met to discuss these, reconciling differences in interpretation to create a unified coding scheme for categorizing the data. New coding categories included usability of PRO platform; improvement of recall of health concerns; promotion of self-evaluation; facilitates honest responses; improves patient-provider communication; expands comprehensiveness of care; enhances sense of being cared for; criticisms/concerns regarding
43% Black, 36% white (Table 1) reported primarily favorable views of self-administered, electronic PROs. PWH unanimously reported finding the the PRO interface easy to navigate and use:

*Easy, and I'm not a big computer person (Male, 57, FL)*

*It was self-explanatory. You hit [the icon that says] "Next". You read and get through with it and go to the next page. It was easy. (Male, 54, FL)*

*The interface was fantastic. Like I said, I'm glad the [progress] bar was there, so you can kind of see where you're going. (Male, 29, ON)*

*I don't really know much about electronics. I have my cell phone and every time I'm using it, if I have a little difficulty, I have to call my kids. But this was kind of fun experience. (Female, 55, ON)*

Patients reported PROs added value to their care in several ways. These included (1) helping feel prepared for their appointment through improved recall of their own health concerns and needs; (2) promoting self-evaluation in psychosocial and behavioral areas; (3) facilitating honest responses, by increasing comfort level in

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**Table 1. Clinical and demographic characteristics.**

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Site</strong></td>
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</tr>
<tr>
<td>St. Michael’s Hospital (Toronto, ON)</td>
<td>10</td>
</tr>
<tr>
<td>Midway Clinic (Ft. Pierce, FL)</td>
<td>20</td>
</tr>
<tr>
<td><strong>Age (mean, range)</strong></td>
<td>48 (21-71)</td>
</tr>
<tr>
<td><strong>Age (category)</strong></td>
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<td>40-49</td>
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</tr>
<tr>
<td>≥60</td>
<td>6</td>
</tr>
<tr>
<td><strong>Female (cisgender)</strong></td>
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</tr>
<tr>
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<tr>
<td>Asian</td>
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</tr>
<tr>
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<tr>
<td>Straight or heterosexual</td>
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<tr>
<td>Bisexual</td>
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</tr>
<tr>
<td>Taking ART</td>
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answering topically sensitive questions; (4) improving patient-provider communication; (5) expanding comprehensiveness of care, and (6) enhancing a sense of feeling ‘cared about’.

**Improves recall of health needs and sense of preparedness for visit**

Most PWH found PROs were a practical tool for helping them remember what issues to bring up with their provider, thereby allowing them to feel better prepared for the visit. It also gave them a better idea of the spectrum of issues that might possibly be discussed.

I think the questionnaire is a good thing to quickly filter out what needs to be addressed...not everybody comes mentally prepared in terms of having questions and a goal, ‘I should have asked at the doctor that. Why didn’t I ask him that when I was there?’ Sometimes you don’t realize that something needs to be discussed until you have to fill out a questionnaire. So that’s a good thing. (Male, 47, ON)

It’s good to have a ‘light bulb’ of certain things to remind yourself to ask. (Male, 39, ON)

...maybe if I didn’t saw it [the PRO questions], and [had not had] an idea of what the question gonna be, the person asked me, I wouldn’t even answer. But just the fact that I already read it and aware of it, so when the question asked, I was more prepared. (Female, 55, ON)

[The PROs] just reminded me of some questions that I wanted to ask my doctors. I didn’t know what my appointment was for or what to expect when I came in today, so it was good just for me to be able to know some questions that I should ask on my own. (Male, 29, ON)

**Promotes self-evaluation**

Several PWH indicated that the PROs prompt them to take inventory of their health status and act as a tool for self-reflection:

[The PROs] make you think about life and what you’ve been up to the past, since the last time. (Male, 57, FL)

Well, I think it maybe helps you look at yourself more clearly and get a better understanding of who you are. (Female, 64, FL)

It make[s] you like kind of just open your eyes to…your life at a certain point. (Male, 21, FL)

The [PROs] make you think...I’m thinking about last time, if I’m doing better at certain things. If there’s anything showing up that I didn’t have before... there’s a lot of depressions and things... just kind of see where I’m at with all that. Because a lot of times, when you’re in it, you don’t know you’re in it, or you don’t think about [it]. (Male, 61, FL)

I actually really liked the question about how the medication – whether it impacts your day. It’s strange…it was kind of nice that it was acknowledged…reading it made it become real, like, “Yes, it does get in the way sometimes.” (Male, 29, ON)

**Facilitates honest responses**

PWH noted that the automated format of PROs helped allow for more honest responses, particularly to psychosocial and behavioral questions, relative to being asked by their provider face-to-face.

[The PROs] ask you questions that nobody – that other people don’t ask you. That’s the way of getting to know how a person really feels inside...sometimes, you don’t normally talk to people like you want to. Friends and family and sometimes you keep stuff all up inside, so you really don’t open up to nobody. (Female, 53, FL)

It’s just easier to answer [PRO questions] that way [on the iPad tablet]...if somebody was asking those questions [in person], it would be like you’re being, I don’t know, on trial. (Male, 57, FL)

Social desirability bias was the key factor in why answering questions on a tablet felt easier than face-to-face conversation:

It’s harder if [your provider is] somebody you know all the time. You don’t want to let them down...you build up a façade. I guess we all do. You know, trying to be somebody that we’re not. Or we think ‘this is how they want us to be’. We do things. But we don’t want people to know about it...[but] the computer is impartial. It’s completely impartial. (Male, 38(a), FL)

Sensitive topics, such as substance use and sexual behavior, were easier to answer on the tablet:

It’s a lot different to [talk about drug use] to somebody because you’re scared of the facial expressions, you’re scared of the reactions. The iPad is not going to look at
you because you say you do crack every day. So you can be a lot more open when you’re [answering questions on] the iPad by yourself. So if you’re not feeling…comfortable talking to a doctor about it at first, it’s a lot easier at least when they come in and they already know. (Male, 21, FL)

I find that it’s easier to answer to an iPad than it is to a person. I found certain questions, like the alcohol question, I was a little more honest on the iPad versus [face-to-face] – because I feel like you’re expecting a judgmental look back, even though my doctor is actually extremely great no matter what I’ve done. Or not done. But the iPad makes it sort of less [judgmental]. It takes away from that, so you don’t have to worry about – because it’s on a sheet of paper, someone else is going to make their look while they’re reading it, so you don’t have to see it. You don’t have to acknowledge it. (Male, 29, ON)

I mean, [PROs] save the doctor and everyone a lot of time asking a bunch of questions that you might not be honest about. You know what I mean? But if it’s just between you and an iPad…[it’s a] tool a little bit more confidential…rather than trying to explain yourself to someone, so…I quit smoking for a year and then my dumb ass started smoking again. And [my provider] found out, because on the questionnaire…because she asked about the smoking…for sure she must have read it, because she ain’t going to know I started smoking again. I aired myself out real good before I come in here. I was going to hide it until [the PRO] asked me the question. I’m like, damn! (laughs)…so it helps you. You got to be a little bit truthful too…it helps. (Male, 45, FL)

I think [PROs] probably to get people to open up…I wouldn’t just randomly go to my doctor and say, “Okay, I have – [this sexual issue]”, no. But just the fact of seeing the question there and get to actually look at the question, look at the [response options], I was able to answer that, yeah. (Female, 55, ON)

**Improves patient-provider communication**

PWH reported feeling that PROs helped improve communication with their provider, particularly by identifying mental health and quality of life needs that might otherwise have gone unaddressed. Some PWH emphasized that by doing so, PROs made the appointment more efficient:

It definitely helps the doctor, because they come in and he already knew certain things…they print it out I guess, and [the provider] kind of looked at a few things and started asking me himself…he already knew where to start. (Male, 57, FL)

I know the doctor would be sitting and asking me questions that probably [are] not relevant…[PROs] kept it focused on what’s going on. (Male, 30, ON)

[Providers] know more…about you. They can go through [the PRO results] and figure out instead of asking. Because a lot of times they see a lot of people every day, so it’s hard to ask them what’s wrong. It’s like I said, it helps them remember…about you. She knew I quit smoking and now I smoke again…without that she wouldn’t know. I think it benefits the doctors as much as it benefits everyone else, because they don’t have to ask a bunch of embarrassing questions. (Male, 45, FL)

A common theme was the sentiment that PROs help improve the tone of communication, by depersonalizing and ‘defusing ’sensitive questions:

If you [as a provider] ask some sensitive question, “So have you done crystal meth or have you did crack cocaine?” Someone could be, “What are you guys asking the question for?” [Laughs]. But…the iPad is a good method, if it’s coming from the iPad. (Male, 27, FL)

…some [questions from providers] can hurt your feelings. They might not intend to hurt your feelings, but it could be the way it comes out. Which they probably wouldn’t mean no harm. But I would prefer [answering questions] on the pad. To me that was much easier and more sensitive, and I got a better understanding, and I just told the truth. But sometimes [providers take] the tone of a person’s boss. To me, that was better on the pad. That was better for me. (Female, 64, FL)

**Expanded comprehensiveness of care**

Several patients appreciated that the PRO assessment increased the general comprehensiveness of their care:

The questionnaire was all things that you think about at different times, but it's all good that it was all compiled into one thing….there's times that I am anxious…there's times that I am worried about my housing or my rent. There's different times that you feel one of those things that was in that questionnaire, so it's good that it's all compiled into one thing. (Male, 39, ON)

It’s sort of a nice little check with the doctor to make sure they’re not missing anything. Because it’s sort of a
structure and it's easy for them to just go right through the list to see if there's anything – there's indicators on the form that say what they should be looking for, which is great, because you might not think it's a problem, but then it is [a] problem, so it's good we would identify it...very valuable. (Female, 65, FL)

Some patients noted the comprehensiveness of PROs by the fact that they covered issues that might not have otherwise been discussed:

...these questions...on the iPad... really did a lot for me because you had a lot of questions that I probably wouldn't have asked the doctor, or she probably wouldn't have asked me. My symptoms. If I'm taking my medication on time. How does the medication make me feel? My anxiety level or my depression level and my insomnia or whatever the case may be. (Male, 54, FL)

[My provider] brought up [my anxiety] briefly...we had a brief discussion about that. He did mention that there's a social worker, maybe to chat, and things like that. Which was great...it's not something I would have brought up if it weren't for the [PROs on the] iPad. (Male, 29, ON)

Enhanced feeling of 'being cared about'

Patients reported that the discussions transpiring from having been asked questions about well-being, mental health, and health behaviors in the PROs helped personalize their appointment and enhanced their sense of being "cared about".

It felt personal, and I felt like, based on what I responded and the doctor briefly touching on or following up on those [things], I felt really impressed to know that, okay, I didn't come in for that! I just thought that, okay, I'm gonna come, do my blood work, blah-blah-blah, and move on. But then it felt a little bit more personal to me, and I felt good about that, to know that there's a little bit of care or relationship building in it... [the PROs were] a conversation starter. I felt like there was a little bit of relationship...deepened based on that. (Male, 30, ON)

It's not like you're just coming in and getting your injections and getting out...it just shows that they are attentive, that they are doing their stuff. (Male, 39, ON)

Criticisms of the PROs

While patients broadly found PROs to be highly acceptable and felt they were likely useful for PWH in general, some patients felt that PROs were less necessary for their own purposes. These patients felt themselves already able to communicate well with their provider:

I already came knowing the questions I wanted to ask my doctor...so being asked the other questions, I was like, "okay, I wasn't planning on this." (Male, 47, ON)

I brought up the fact that I was depressed...that's what I always do with them. I'm very straightforward. (Female, 37, FL)

I put it on myself to speak about [my health issues], if there's a change in something. (Male, 38[b], FL)

Some patients felt the issues or behaviors addressed by the PROs were not relevant to them:

There wasn't really anything in [the PROs] that was new or made me think about something else...if I was a different patient, I think it could've spurred me to ask different questions...or maybe to be more thoughtful about, "Hey, is this a problem," [e.g.,] if talking about drug use. But it didn't change much for me. (Male, 54, FL)

Another felt historical questions to be less relevant, given that their provider already knows them well:

[My drug use] was over 20 years ago...I've been good, and I don't do hard drugs...so the things that are going on in my life right now, have nothing to do with what I did that many years ago. And they know that. They know everything. (Female, 37, FL)

Some felt the questions about sex/sexuality were too personal:

I was really taken back. The sex questions were very direct. I was like, "Really? Seriously?" (Male, 51, ON)

Sexuality is not important. If you're asking about those things, it's not important...that's not something medical, that's just your private life, who you're screwing and what gender you want to be. (Female, 54, FL)

As far as your [sex] partner – as far as [whether they have] HIV...if he is or if he ain't. That's not for us to say. I thought that was a little personal. (Female, 57, FL)

Some patients felt that the PROs lacked context when answering, and preferred to answer questions in person
to humanize the experience and provide appropriate context:

The iPad's good... [but] I'd rather talk to someone one-on-one. Talking one-on-one, you get a feeling of someone instead of on the iPad...it's a machine. You talking to someone one-on-one, they can get to how you feeling and do a little one-on-one at the person you talking to. (Male, 54, FL)

I think [the PRO questions] are more appropriate in person...I think it should be more of a human touch. (Male, 47, ON)

On the iPad, two or three questions where I marked, it was like, okay. I'll just mark this because I can't explain why I feel this way, because it's not a person. (Female, 53, FL)

Two patients expressed concerns surrounding the use of PRO data and its confidentiality, fearing potential legal consequences of their response. As one patient summarized:

I find that it's the scariest part about being...HIV positive is the law...you cannot even engage in oral sex...unless it's protected, you have to disclose. That's why it's awkward when those [sexual risk behavior] questions came up. I was just like, I don't know how to answer this question, because I don't want to put myself in a position where, yes, I'm disclosing we might be having unprotected sex, but can this sort of bite me in the end. (Male, 29, ON)

DISCUSSION

PWH experienced electronic, self-administered, tablet-based PROs as easy to navigate and use, and reported PROs added value to their care in several ways. PROs improved their preparedness for the visit by helping to recall health needs; and the PROs promoted self-evaluation, as a comprehensive means of 'taking stock' of their overall health, particularly mental health. PWH valued the use of PROs as a mechanism for disclosing highly personal or potentially stigmatizing symptoms and behaviors, particularly depressive symptoms, sexual behavior, and substance use; most, but not all, found it easier to convey these to an "impartial" platform prior to the appointment rather than being asked verbally by the provider. PWH described improved communication with their providers, in part due to feeling able to answer questions more honestly, but also due to the comprehensiveness of the assessment across several health topics. PWH believed that the provider receipt of PRO results prior to the appointment resulted in discussion of issues that otherwise might have been overlooked. As a result, several patients reported experiencing an enhanced quality of care that felt highly personalized, comprehensive, attuned to hidden needs, and focused on well-being.

Our findings echo evidence from primarily HIV and cancer care (Fredericksen et al., 2020), in which PROs were found acceptable and useful to patients across a broad range of populations and care modalities (Crane et al., 2007; Wolpin et al., 2008; Howell et al., 2015; Sarabia et al., 2015). Patients have found electronic/computer-based PRO assessments easy to use (Basch et al., 2005; Basch et al., 2007; Mark et al., 2008a; Mark et al., 2008b; Wolpin et al., 2009; Dunn et al., 2016; Sinha et al., 2020), useful for recall and promoting discussion of symptoms (Basch et al., 2005; Mark et al., 2008a; Mark et al., 2008b; Mark et al., 2008b; Sarabia et al., 2015), and helpful in improving providers' awareness of their needs (Detmar et al., 2002; Basch et al., 2005, 2007; Thewes et al., 2009). The use of PROs has helped patients feel more in control of their own care (Fredericksen et al., 2019). Patients also have found that PROs help increase honesty with their provider, as well as themselves; indeed, prior work comparing computer-based assessments with interviewer-based assessments notes higher accuracy when using the former when reporting sensitive information (Sinha et al., 2020). Our interviews suggest PWH perceive similar value of PROs found in other clinic populations, with an emphasis of the value of an enhanced communication dynamic afforded by reducing social desirability bias.

While overall PWH found PROs to be valuable, some expressed reservations and concerns which are instructive for considering implementation of PROs. Some felt that the issues assessed, such as drug use, were not relevant personally; for example, if without history, or only distant history, of drug use. This highlights the need to tailor PROs as much as possible to individual patient needs. This is addressable in several ways. One is the use of carefully considered skip patterns, easily programmed in electronic PROs; for example, a patient would be asked about specific types of drug use only if they had indicated lifetime use of that drug. In addition, algorithms can help administer certain PRO measures with varying levels of frequency based on patients' historic responses. For example, a patient over 50 that has reported no prior drug use history might be shown drug use items only annually; a patient indicating IPV on a previous assessment might be shown the same items at each visit, whereas a patient indicating no prior history might be shown these items less frequently. Others found certain PRO items, particularly the items querying sexual risk behaviors, to be too personal, highlighting the
usefulness of allowing patients to “skip” questions if they wish. To help offset these concerns, introductory language could be included at the beginning of the assessment indicating that the PROs are meant as a broad screening tool, and that not all questions are necessarily applicable to individual patients.

Some PWH reported concerns about PROs lacking sufficient contextual detail to accurately represent or explain their behaviors, which was felt to be easier in a human interaction. A small number of PWH expressed concerns regarding confidentiality of the data and uncertainty regarding the purpose and uses of the assessment. In this population, tasked with navigating HIV-related stigma and concern for ‘feeling judged ’ regarding health behaviors, the use of data and confidentiality protocols should be made clear, ideally by the clinic personnel that are introducing the assessment. Framing the purpose of the PROs to PWH at first administration, in fact, is critical to their ongoing relationship with PROs; PWH should be informed that their providers will see the answers, that they have a choice in whether or not they answer particular questions, and that the PROs are intended as a tool for ensuring their needs are heard in their care.

With the goal of promoting the healthiest patient outcomes possible among PWH, the argument for implementing PROs into clinical HIV care is strong. First, as an increasingly aging population, PWH are often managing multiple chronic conditions and reporting on their associated symptoms; PROs, with the ability to quickly and comprehensively assess many symptoms, are highly effective for this purpose. Second, relative to other conditions or disease groups, the health of PWH is interwoven tightly with a social dimension, which includes navigating social support and managing perceived and real HIV-related stigma, with mental health implications. Related symptoms may evade report or detection when assessing solely in-person; hence, PROs offer a more honest assessment of patient needs. Third, for PWH, healthy outcomes often rely on accurate reporting to providers of health behaviors that may be embarrassing or stigmatizing to admit to in-person, such as substance use, HIV/STI transmission risk behavior, and ART adherence; again, PROs offset social desirability bias that often obscures these behaviors. These attributes, supported by evidence of high patient acceptability, usability, and perceived value, underscore the importance and potential of electronic, self-administered PROs in optimizing clinical HIV care.

**Strengths**

We interviewed PWH from two geographically diverse clinics, with highly diverse patient populations.

**Limitations**

PWH willing to be interviewed may not be representative of the population of PWH that self-administered the PROs in these clinics. We did not track interview refusal rate, and we lacked data on socioeconomic status which may preclude our ability to characterize those agreeing to participate vs. those who declined. There exists the possibility that reviewers external to the study may reach different conclusions. We also acknowledge that this study utilized a full-time research coordinator at each site who ensured smooth implementation of the PRO workflow for each patient; a lack of this resource in other settings may yield a different experience from the perspective of the patient.

**Conclusion**

PWH receiving care in two North American HIV clinics found electronic, self-administered tablet-based PROs administered on-site immediately before the appointment to be useful for prioritizing discussion topics with their providers, helping initiate discussion on sensitive issues, and improving comprehensiveness of and satisfaction with care.

**CONFLICT OF INTERESTS**

The authors have no conflict of interest.

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